

Defining health professional competence for working with teenagers and young adults with cancer: A modified e-Delphi survey



Version 2.1, 2nd January 2014

Protocol authorisation

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WORKSTREAM 1 LEAD

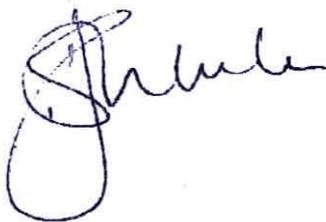
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A handwritten signature in black ink, appearing to read 'Faith Gibson', with a long horizontal stroke extending to the right.

Date: 2nd January 2013

CHIEF INVESTIGATOR

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Date: 2nd January 2014

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Document control

Version	Date	Author	Application reference	Notes
1.0	24/06/13	RM Taylor	UREC 1335	First application to London South Bank University Research Ethics Committee
2.0	01/10/13	RM Taylor	UREC 1335	Corrections following review by the University Research Ethics Committee
2.1	02/01/14	RM Taylor	UREC 1335	Change the timelines

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Background

Teenage and young adult (TYA) medicine has emerged as a distinct speciality in healthcare, acknowledging the core tasks required to enable a young person to transition from childhood to adulthood (1). This is especially so in cancer, where it has been recognised in 2005 in Government policy in the United Kingdom (2). The *Improving Outcome Guidance* issued by the National Institute for Health and Clinical Excellence (NICE) guidance dictated that young people aged 15 – 18 receive care in a principal treatment centre (PTC) and those aged 19 – 24 years should have unhindered access to ‘age-appropriate’ care (2). The implementation of these guidelines is currently on-going, accompanied by a national evaluation of TYA cancer services (BRIGHTLIGHT, NIHR PGfAR RP-PG-1209-10013). Additionally, the *Improving Outcomes Guidance* suggested the composition of the multi-disciplinary team, mimicking those proposed by the Adolescent and Young Adult Oncology Programme Review Group in the United States (3). The NICE (2005) guidance is summarised in Table 1.

Table 1: suggested members of the multi-disciplinary team (2)

Diagnosis ^a	Treatment ^a
Oncologist/haematologist Radiologist Surgeon/neurosurgeon Pathologist/cytogeneticist Clinical oncologist	Treating oncologist Key worker ^b Paediatric haematologist Specialist nurses Nurses from inpatient and day care units Specialist pharmacist Dietician and other appropriate allied health professionals Paediatric oncology or other speciality outreach nurse/key worker ^b
Psychosocial support	Palliative care
Treating oncologist and haematologist Key worker ^b Play specialist; activity coordinator/youth worker Psychological services professional Specialist outreach nurse Appropriate allied health professionals Teacher Social worker Nurses from inpatient and day care units	Lead clinician Key worker ^b Palliative care specialist/oncologist/haematologist Social worker Specialist outreach nurse Specialist pharmacist Psychological services professional Appropriate allied health professional

^a Medical staff represent tumour-specific or paediatric expertise

^b See section on continuity of care (key worker may come from any of the disciplines involved in the MDT)

While suggestions have been made as to the core members of the multi-disciplinary team, nothing has been proposed as to their level of competence or expertise. An exploration

among a group of experts in the United States provided a template for TYA education, mainly focusing on medical knowledge and care delivery (4); however, this involved ‘experts’ from a limited representation of the multi-disciplinary team and did not specify competencies that reflected the tasks, attributes and contexts that are required to care for young people. Similarly, recent guidance on the delivery of TYA cancer care in the UK notes “the best standard of care for teenage and young adult patients is undoubtedly provided by clinicians who have been specifically trained to care for them” (5). The recommendation was for professionals to participate in TYA specific education, but no guidance was provided as to what this should involve or to what level of competence professionals should aspire to.

Competence can be defined as having knowledge, skill and experience to be able to fulfil the requirements of one’s professional role (6). Identification of competence is an essential aspect of high quality, safe and cost-effective care. Furthermore, defining competency is essential in: education – for curriculum content development, assessment strategies and developing competency frameworks; practice development; and for management – to aid recruitment and the skill mix of the work force (7).

As part of the feasibility and pilot work undertaken for BRIGHTLIGHT, a workshop was undertaken with health professionals to start defining the skills and attributes of health professionals working in specialist TYA cancer care. This was integrated with data collected at a Teenage and Young Adult with Cancer (TYAC) annual meeting to provide a catalogue of key competencies. This scoping exercise provided an extensive number of competencies. The top five were identified as:

- Expertise in treating paediatric and adult cancers;
- Understanding cancer
- [Delivery of] appropriate information about the disease;
- Bridge between TYA need for information and parental reaction to withholding information;
- Giving mutual respect (8).

The aim of the current study is to progress this preliminary work to provide international consensus on the competencies required by health professionals to provide specialist care for TYA with cancer, in order to provide the evidence to influence education and training.

Study design

Formal or structured methods are commonly used to reach a consensus in the absence of research evidence or where there is a desire to gather opinion and initiate debate (9;10). The advantages of this method over informal committees includes: offering more transparent ways of synthesising individual judgments; reducing the influence of dominating personalities and ‘group think’; and the provision of valuable information on the extent and

reasons for differences of opinion (11). A commonly used formal consensus method is the Delphi technique, a method which involves two or more rounds of postal or on-line questionnaires. This allows involvement of large and geographically dispersed groups of participants; avoids the risk of some individuals exercising undue influence; and is more reliable than its commonly used alternative, the nominal group technique (12-14). A classical Delphi survey begins with an exploratory questionnaire containing mainly open ended response questions, in which to develop subsequent questionnaires (15;16). As scoping work has previously been undertaken (8) our work will use a modified Delphi survey (17) using online methods. The responses from round one will be analysed and returned to panel members in a second round survey to gain consensus of the core competencies. While there is no fixed number of rounds in a Delphi survey (17), other similar studies suggest consensus will be reached after two rounds (8;18-21).

Sample

Participants to the expert panel will be recruited through purposive and snowball sampling methods to create a database reflecting not only the range of health professionals within the multi-disciplinary team but also representative of the international community.

Definition of 'expert'

The Delphi technique does not use a random sample which is representative of the target population, but rather employs 'experts' as panel members. There is little consensus as what defines an 'expert' (22) and therefore 'expert' for the current Delphi study is defined as any health professional working in TYA cancer care for a minimum of 12 months.

It is hoped that involvement of a panel of experts with a range of experiences will help to: classify the level of competence according to career stage, i.e. what competence is expected of professionals new to TYA cancer care versus those expected of more senior members of the team; identify any country-specific competence; and determine if there are any competencies that are profession specific.

Identification of health professionals

The aim will be to include as diverse a range of the multi-disciplinary team (MDT) as possible therefore health professionals will be identified through a number of mechanisms:

1. Purposive – invitation will be sent through professional organisation membership lists (Appendix 1), for example, TYAC (Teenagers and Young Adults with Cancer), International Society of Paediatric Oncology (SIOP), European Network for Cancer Research in Children and Adolescents (ENCCA), Children's Oncology Group (COG). Invitations will also be sent through key TYA cancer charities, for example, Teenage Cancer Trust, CanTeen (Australia/New Zealand), SeventyK.

2. Purposive – literature reviews on TYA with cancer (23;24) have identified health professionals who may be working in TYA cancer care. Invitations will be sent to contact email addresses supplied with publications (Appendix 2).
3. Purposive – invitations will be sent out from the lead TYA clinician and senior nurse in each PTC, throughout members of the TYA multi-disciplinary team (including members who are the TYA designated Trusts).
4. Snowball – each invitation sent to professionals identified through purposive methods will request that the invitation is forwarded to all members of their TYA multi-disciplinary team. Specific emphasis will be to include professionals other than nursing and medical staff to try and reflect the breadth of expertise and range of professionals working in the field.

Sample size

There is no consensus as to the optimum number of participants in a Delphi survey (17). As a heterogeneous sample (recruiting from a number of countries, in a range of designations), it is recommended that there is a large expert panel (26); however, there is no consensus as to what is classed as large. The current survey will therefore include all professionals who express an interest to participate, fulfilling the definition of 'expert'.

Recruitment procedure

A strategy shown to improve recruitment and retention into a Delphi study is through personal invitation (25). While an open invitation will be extended generally to all professionals in identification strategy 1, personal invitation will be sent to those identified through authorship on publications (strategy 2). Professionals will be contacted with an introductory email (Appendix 1) and information about the survey and what participation will involve (Appendix 2). This will be to identify interest in taking part and seek the names of other members of the MDT they feel would contribute to the survey. From the outset, it will be made clear to professionals exactly what participation will require, and over what time period. Gaining commitment to participate and ensuring professionals have a sense of ownership of the study is a further mechanism to increase response to subsequent rounds (17). Professionals who want to become members of the expert panel will be asked to complete and return a registration and agreement form (Appendix 3).

While knowledge of participation between professionals will be anonymous, panel members will be known to the research team in order that changes in response between rounds can be analysed and reminder emails can be sent. Professionals will be assured of anonymity and confidentiality.

Methods

First round questionnaire

Traditionally the first round questionnaire in a Delphi survey contains open ended questions to enable a 'scoping' of participants views (17). Our previous study generated a comprehensive list of competencies (8), which forms the content for the first round of the Delphi survey (Appendix 4). Additional information includes panel member name, designation, location, educational attainment and time working in TYA cancer care. The majority of questions have closed-ended responses using 3 or 5-point Likert scales (strongly agree – strongly disagree). However, as the questions for the first round questionnaire were developed by professionals based in the UK, a number of open-ended questions are included to ensure these fully reflect the opinion of professionals in other countries. The questionnaire will be administered through a web-based survey programme.

Procedure

After confirming participation and on the specified date, participants will be sent an email invite to activate the questionnaire. (Participants can request the survey as a word document to be returned through email or post). In line with recommendations (17;27) three reminders will be sent on a weekly basis if the survey has not been returned. This procedure will be repeated for each round of the survey. Participants who do not respond to round 1 will not be included in further rounds. It is important that as short a period as possible elapses between rounds of the survey in order to maintain interest by the panel and maximise retention (16;17;25), and therefore there will be a maximum of two months between rounds.

Round two questionnaire

Only items where there is agreement (described below) will be included in the round 2 questionnaire; which will include only scaled items. The distribution of ratings for each item will be displayed on the line below the Likert scale on the second round questionnaire, which will be personalised such that each participant is reminded of their own first round rating for each item (28). The round 2 questionnaire will include an additional scale to discriminate competence for professionals in TYA cancer care to those in child or adult. It is envisaged that consensus will be reached after two rounds; however, if there is wide variation in agreement after the second round a third round will be conducted.

DATA ANALYSIS

A mix of quantitative and qualitative methods of analysis will be employed for the first round questionnaire. Qualitative content analysis will be used to analyse responses to open ended questions. These will be included as additional statements in the second round questionnaire if they have not previously been included. For each item, the level of group

support will be indicated by the median and, to enhance the transparency of the results, the extent of disagreement for each item will be given by the group's mean absolute deviation from the median, i.e. the average distance (on the nine-point Likert scale) of participants' ratings from the group's median rating (29). Items will be ranked and reported according to the medians. Medians of 7-9 will be defined as strong support, 4-6.5 as moderate and 1-3.5 as weak. Mean absolute deviation from the median will be calculated and the level of agreement will be categorised according to thirds of the mean absolute deviation from the median (low >1.41, moderate 1.08-1.41, high <1.08). These summaries will also be calculated in subgroups according to country, profession and experience.

To report in more detail the stability consensus and convergence of agreement between the rounds, which will further indicate whether a third round will be required, an accessible analytical approach will be used (30). This involves generating three graphs:

1. **Fountain graph:** every item's median and mean absolute deviation is plotted, which shows the extent of the panel's opinion and the amount of agreement for all of the items in the Delphi. Comparison of fountain graphs in each round indicates the amount of change in opinion across the whole survey.
2. **Item graph:** the median and mean absolute deviation is plotted for each item, which demonstrates the change in the level of group opinion and group agreement between rounds.
3. **Trajectory graph:** the median and mean absolute deviation is plotted for a group of items that feature within an identified category, e.g. skill, knowledge, attitude. A scatter plot is created and the dots for each plot are then joined up. This shows the trajectory of the items across appearances.

Ethical considerations

The study does not require NHS Research Ethics approval as participants are healthcare professionals; however, the study will be approved by London South Bank University Research Ethics Committee. An invitation email and information sheet will explain the purpose of the survey and what participation will involve (Appendix 1 and 2). Professionals will be made aware that participation is pseudo-anonymous, so the research team will know the panel of experts, but they will remain anonymous to others in the panel. This information will be repeated in the covering information accompanying each round of the survey. Consent to participate will be through completing the registration and agreement form (Appendix 3).

Contact with the research team will be through a study specific email address (hscBRIGHTLIGHT@lsbu.ac.uk) and identifiable information will be stored in a password-protected database kept on a secure server.

Cross-cultural considerations

As the Delphi survey is being conducted internationally, it is important cultural differences are taken into consideration; however, as resources for the study are limited the pragmatic decision has been made to not translate the survey into multiple languages. As with other cross-cultural Delphi surveys (31), the questionnaire will be available in a single language (English). It is acknowledged that a limitation of the survey is non-English speakers are disadvantaged by not having the opportunity to respond; although it is noted that this has not been a barrier in a European survey conducted by ENCCA. Translation through online software will be discouraged because the quality of translation is questionable (32). In the first round there will be open ended questions; panel members are encouraged to complete this section in English but they may prefer to complete this in their native language. If this occurs then rather than lose potentially valuable responses, they will be translated into English to be included in the analysis. Cultural variation will be determined in sub-analysis at each round of the survey, where any potential bias will be identified.

Management of the study

It has been recommended that the facilitation leader of a Delphi survey is an 'expert in research data collection and not a stakeholder' (21). The day-to-day running of study will therefore be conducted by the BRIGHTLIGHT Project Lead and Research Assistant who do not have a clinical interest in TYA cancer care. This will be overseen by the Workstream lead and study progress will be reviewed on a monthly basis by the BRIGHTLIGHT Core Research Team.

Timelines

March 2013:	Research proposal and 1 st round questionnaire developed
June 2013:	Application submitted to London South Bank University REC
Oct – Dec 2013:	Identify experts in the literature Identify professional organisations around the world and gain permission to send an invitation through group emails
Jan - Feb 2013:	Invitation sent to professionals to participate
March 2014:	1 st round questionnaire distribution Three reminders sent on a weekly basis to non-responders
April 2014:	Round 1 data analysis
May 2014:	Development of Round 2 questionnaire
June 2014:	Round 2 questionnaire distribution Three reminders sent on a weekly basis to non-responders
July 2014:	Round 2 analysis
July – Aug 2014:	Stability analysis

[Round 3 questionnaire development & distribution if a further round is required]

October 2014:	Final report and draft publication
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Appendix 1: Invite to join the expert panel

Subject heading: Invite to join an expert panel

Dear Colleague,

We would like to invite you and members of your multi-disciplinary team to join an expert panel for a Delphi survey to define the competencies required to care for adolescents and young adults with cancer. We have attached information about the study and what participation in the expert panel will involve.

We would like to involve as wide range of professionals representing the multi-disciplinary team as possible, from as many countries as possible so we would be grateful if you could forward this email and attachments to as many of your team as possible.

If you have any questions please don't hesitate to contact the team. If you would like to take part, please complete the attached registration form and return to hscbrightlight@lsbu.ac.uk.

We look forward to hearing from you.

Best regards

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Appendix 2: participant information sheet

BRIGHTLIGHT Logo/LSBU headed paper

Defining health professional competence for working with adolescents and young adults with cancer: A modified e-Delphi survey

Health professional information sheet

We are inviting you to join an expert panel for a Delphi survey that will commence later this year. Before you decide to participate we want to explain more details about the study, why it is being done and what participation will involve.

What are the aims of the survey?

The aim of the survey is to gain international consensus on the competencies required by members of the multidisciplinary team to care for adolescents and young adults with cancer. We would like to identify those competencies specific to adolescent and young adult care that differs to those required for looking after children and adults with cancer.

Why have you been invited to take part?

For the purpose of the Delphi survey we are defining 'expert' as a member of the multidisciplinary team who has worked with young people with cancer for more than 12 months. You have been invited to join the expert panel because you have either been identified by the BRIGHTLIGHT Team as being an expert or you have been nominated by a colleague.

What will you have to do?

A Delphi technique is a method where a panel of experts are asked to rank statements in order of importance in a series of rounds to reach a consensus. The current Delphi survey is modified because the information normally collected in the first round using open ended questions or qualitative methods has already been collated and presented¹. The first questionnaire you will therefore be asked to complete contains the skills, knowledge and attitudes that have already been identified as being an important aspect of competence for caring for adolescents and young adults. You are asked to rate each item on whether or not it is important. There are spaces for you to add anything else that you think is missing. The first questionnaire contains 97 items and will take approximately 10 minutes to complete.

You will receive a second questionnaire between 4 – 8 weeks after the first. This will only contain the items where there has been agreement. It will contain your response for each item compared to the

¹ Gibson F, Fern L, Whelan J, Pearce S, Lewis IJ, Hobin D, Taylor RM (2012) A scoping exercise of favourable characteristics of professionals working in teenage and young adult cancer care: 'thinking outside of the box'. *European Journal of Cancer Care* 21: 330-339 (available on request)

How do you take part?

If you want to be an expert panel member for the adolescent and young adult professional competency survey, please complete the registration form accompanying this information sheet and email it to hscbrightlight@lsbu.ac.uk.

As we want representation of professionals from the multi-disciplinary team we would also be grateful if you could forward this information to your colleagues.

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Appendix 3: Registration form for Expert Panel Membership

BRIGHTLIGHT Logo/LSBU headed paper

Registration and agreement to be a member of the Adolescent and Young Adult Health Professional Competency Delphi Survey Expert Panel

Completing and returning this registration and agreement form you are consenting to the following:

1. That your contact details and information about you can be kept on a secure, password protected server that is accessible by the members of the research team named on the information sheet. (These details will be deleted after sending you the final report).
2. To complete a maximum of three questionnaires over seven months between March 2013 and September 2014.
3. Comments provided in the open-ended response sections can be used verbatim, with any identifiable information removed.

Date:

Title:

Forename:

Surname:

Designation:

Work address:

Telephone number (including country code):

Email address:

Short description of adolescent and young adult cancer care experience

Appendix 4: Round 1 survey

The Adolescent and Young Adult Health Professional Competency Delphi Survey

Introduction

This questionnaire is about the skills, knowledge and attitudes (competence) of health professionals caring for adolescents (teenagers) and young adults with cancer. Through gaining international consensus on core competence this will provide an evidence-based framework to develop future education and training.

All the information you provide will be completely confidential; no one outside of the BRIGHTLIGHT Team will know the names of anyone who has taken part or where they work. An anonymised dataset will be produced from the information gathered from everyone who has taken part and will be kept securely by the BRIGHTLIGHT Team. In the second round you will receive your results in comparison to the average results of the whole panel.

BEFORE YOU FILL IN YOUR SURVEY PLEASE READ THE INFORMATION BELOW

The survey is divided into 4 sections based on the results of a scoping exercise conducted in the United Kingdom (Gibson et al. EJCC 2013, 21: 330-339).

All the questions that require 'tick box' responses are compulsory.

Please read each question carefully and tick the box which comes closest to your views, checking you have answered all questions.

Each section has an additional comments option. If you would like to add other areas of competence not listed, please write in the space provided.

Once you have finished please take a minute to check you have answered all the questions that you should have answered.

This questionnaire consists of 97 items and should take no longer than 10 minutes to complete. Thank you in advance for your time.

Responses for sections 1 – 4 are a nine-point scale with three anchors: (1) 'not important'; (5) 'of moderate importance'; (9) 'extremely important'

Section 1: Skills

The following SKILLS have been proposed as being important for caring for adolescents and young adults with cancer. Please indicate how important you think this SKILL is.

PLEASE TICK ONE BOX ONLY FOR EACH ROW

Being able to:

1. ...cope emotionally
2. ...treat information sensitively
3. ...show compassion
4. ...be empathetic
5. ...be patient
6. ... balance between delivery of care and spending time with the young person
7. ... identify the impact of disease on young people's life
8. ...assess young people's social needs
9. ...assess young people's psychological needs
10. ...identify when care could be better delivered by other professionals or in another organisation
11. ...deliver patient centred care
12. ...promote peer interaction
13. ...balance between patient and family centred care
14. ...promote and enable choice
15. ...empower young people
16. ...provide holistic care
17. ...work in partnership with young people
18. ...be flexible in how care is delivered
19. ...provide individualised care
20. ...befriend young people but not lose professional identity
21. ...work as part of a team
22. ...provide palliative care

23. Having tolerance
24. Being part of a network of colleagues interested in adolescent and young adult care
25. Be aware of professional boundaries
26. Have excellent clinical skills

Are there any skills you think are important for caring for young people with cancer that are not listed above?

PLEASE WRITE IN IN THE BOX BELOW

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Section 2: Knowledge

The following KNOWLEDGE has have been proposed as being important for caring for adolescents and young adults with cancer. Please indicate how important you think this KNOWLEDGE is.

PLEASE TICK ONE BOX ONLY FOR EACH ROW

Understand:

1. ...cultural issues
2. ...issues relate to death and dying during adolescence and young adulthood
3. ...developmental issues related to emerging adulthood
4. ...family issues
5. ...issues related to risk-taking and measures to limit this
6. ...transition and how this impacts on young people at varying stages of development
7. ...environmental issues impacting young people's health
8. ...the importance of peer relationships and how these may be promoted
9. ...the importance of restoring normality
10. ...wider issues for young people, e.g. social media

Know about

11. ...current therapies
12. ...availability of clinical trials for this age group
13. ...new drugs
14. ...normal psychological development
15. ...impact of cancer on psychological development
16. ...side-effects of treatment and how this might be different to those experienced by children or older adults
17. ...pediatric oncology
18. ...adult oncology
19. ...fertility preservation
20. ...normal adolescent physiology

21. Know the ethical issues related to caring for young people with cancer

22. Have up-to-date knowledge of the policies, nationally and locally, related to caring for young people with cancer
23. Know ways of developing coping strategies
24. Importance to maintain professional development
25. Able to share knowledge
26. Have a formal cancer-specific qualification
27. Have a qualification specific to adolescent and young adult cancer
28. Know how to provide age appropriate care

Are there any areas of knowledge you think are important for caring for young people with cancer that are not listed above?

PLEASE WRITE IN IN THE BOX BELOW

Section 3: Communication

The following COMMUNICATION skills have been proposed as being important for caring for adolescents and young adults with cancer. Please indicate how important you think this COMMUNICATION is.

PLEASE TICK ONE BOX ONLY FOR EACH ROW

Ability to:

1. ...act as an advocate for young people
2. ...tell young people about all aspects of their disease
3. ...liaise with other professionals on young people's behalf
4. ...facilitate communication between young people
5. ...resolve conflicts between young people
6. ...resolve conflicts between young people and health professionals
7. ...resolve conflicts between young people and their families
8. ...listen to young people's concerns
9. ...talk about difficult issues
10. ...act as a bridge between young people and their parents
11. ...allow young people time to come to their own solutions
12. ...facilitate care between different organisations/agencies
13. ...provide emotional support young people
14. ...provide bereavement support when peers pass away
15. ...speak to young people in terms that is familiar to them while retaining a professional boundary
16. ...talk to young people about sexual issues
17. ...provide life skills support

18. ...discuss the impact of disease on aspirations
19. ...provide career, education or training advice

Are there any communication skills you think are important for caring for young people with cancer that are not listed above?

PLEASE WRITE IN IN THE BOX BELOW

Section 4: Attitudes

The following ATTITUDES have been proposed as being important for caring for adolescents and young adults with cancer. Please indicate how important you think these ATTITUDES are.

PLEASE TICK ONE BOX ONLY FOR EACH ROW

Have the following personal attributes:

1. Friendly and approachable
2. Resilience
3. Self-awareness
4. Caring
5. Sense of humour
6. Be able to laugh at yourself
7. Honesty
8. Be positive
9. Be relaxed
10. Be calm
11. Be respectful
12. Be consistent
13. Have energy
14. Be motivated
15. Ready for a challenge
16. Open to new ideas
17. Be creative

18. Willing to learn
19. Ability to learn from others
20. Be committed to caring for young people with cancer
21. Be passionate for working with young people
22. Be a member of a adolescent and young adult with cancer professional body
23. Have attention to detail

24. Able to have a work-life balance

Are there any attitudes you think are important for caring for young people with cancer that are not listed above?

PLEASE WRITE IN IN THE BOX BELOW

Section 5: about you

Round 2 of the Delphi survey will contain your response from round 1 in comparison to the average of the expert panel as a whole and therefore we need to be able to identify you. However, anonymity can be assured and your response will be kept confidential.

Please can you confirm:

Title

Forename

Surname

Designation

Work address

Country

Email address

Thank you for participating. If you have any questions, please contact the team on hscbrightlight@lsbu.ac.uk. Alternatively, please refer to our website...